

# Proxy Parent Foundation newsletter

WINTER 2017 ISSUE 17

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## PROXY PARENT FOUNDATION

Proxy Parent Foundation offers  
two services.

We are Trustee of the PLAN of  
California Master Pooled Trust,  
which is open as a trust vehicle  
for any disabled person in  
California.

We provide Personal Support  
Services for beneficiaries of our  
Special Needs Trusts who have a  
mental illness or brain disorder.

Just like a loving family, we  
coordinate public and private  
social services and medical  
care while providing family-like  
attention to help the person  
improve his or her quality of life.

Proxy Parent Foundation is a dba  
of Planned Lifetime Assistance  
Network (PLAN) of California, a  
501(c)(3) nonprofit corporation.

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## Welcome

As we have evolved as an organization and our trust, personal support, and administrative services have grown, as much as we would have liked to, we have found it more and more difficult to stay in touch with our many friends and clients, including obviously all of you. Realizing that, we have added someone to our staff to provide the outreach and follow-through to keep the lines of communication open with those we serve, our friends and the broader community.

That being said, I am very pleased to introduce the latest member of the Proxy Parent Foundation staff, Kimberly Alsabery, our new Communication and Client Relations Officer. She has been on board since August and many of you have already spoken to her. For those who haven't, I am sure you will find her as engaging and deeply committed to our mission as we have.

I will let Kimberly provide her own introduction next, but following that, I am sure you will also enjoy the remaining articles—

The first is by Board Member, Baron Miller, who addresses the importance and difficulty of finding a proper trustee of a special needs trust, and why a pooled trust, such as ours, can provide the best solution.

Next, Nancy Nigrosh, wife of our Director of Social Services, Bruce Lewitt, relates a true to life vignette (name changed to protect the innocent) that pretty much summarizes what our personal support services are all about in a simple yet meaningful way which I'm sure you will all be able to relate to.

And of course, there is the most recent book review by Joe DeCarlo, Board President— "Bi-polar Disorder for Dummies". Wow, does that title speak volumes. Or not.

Finally, I am also honored and pleased to announce the following donation challenge: Two of our Board Members, Tom Stevens and Carla

Jacobs, through the Roy W. Smith Foundation, have promised to match all 2017 contributions, made to Proxy Parent Foundation for up to \$25,000 each, for a total of \$50,000. Please help us take advantage of their wonderful offer and commitment to our mission by giving whatever charitable gift you are able.

Most of all, Happy Holidays and New Year to you and yours!!

GARY M. CHANG

*Director of Legal Affairs*

## Dear Friends and Family of Proxy Parent Foundation,



Please allow me to introduce myself to you, my name is Kimberly Alsabery and I am joining Proxy Parent Foundation as the Communications and Client Relations Officer. As a California native with a familial connection to the disabled community, Proxy Parent Foundation is particularly near to my heart. I am a graduate of Arizona State University with an extensive marketing and development background. I look forward to marrying my professional expertise with my personal experience to ensure the vitality and growth of the organization for many years to come. After years of health struggles and a year in hospice, my blind and mentally disabled aunt passed away this past February. I know first-hand the struggles of managing a loved one's care and finances. The passing of my aunt brought me to seek a position where I could utilize my experiences to help others in the disabled community. I am excited to join Proxy Parent Foundation, where I strive to answer the question, "Who will care when you're not there?" Please feel free to contact me at [kalsabery@proxyparentfoundation.org](mailto:kalsabery@proxyparentfoundation.org)



or 714.997.3310 if you have any questions or would like to share your stories with me.

## Who to Designate as a Trustee?

Clients of mine who want to establish a special needs trust for someone with a mental illness frequently share a common challenge: who to designate as the trustee? It is a daunting problem, since the trustee often is expected to try to fill the shoes of the person establishing the trust, a person who likely has long been dealing with the formidable job of caring for a person with mental illness. How is someone else going to do what we do, with our knowledge gained from experience, with our devotion forged by love, compassion, responsibility and duty?

Clients ask me what do I think, who do I recommend. There are numerous options—family members and friends, private fiduciaries, financial institutions, non-profit organizations, financial advisors, attorneys and accountants. Depending on the situation, each has something to offer as a potential trustee. Each has drawbacks too.

I advise against attorneys and accountants due to the size of their fees—if they are affordable, then there is enough money to pay for an institutional trustee, which would have the added advantage of being an experienced investor. Attorneys and accountants, I think, can make good trust protectors—those who would appoint and terminate trustees, who would receive financial and personal reports from trustees, who would serve as overseers but not day-to-day operators of a trust.

I advise against financial advisors due to potential conflicts of interest and perhaps lack of knowledge of the effects of mental illness, and often advise against financial institutions for the same reason.

Family members and friends can be a good option, depending on their willingness, their interpersonal and financial skills, and whether their relationship with the trust beneficiary would be put in jeopardy by their control of assets and distributions.

Private fiduciaries – those persons who are licensed by the State to hold others' assets, and who are recognized by the courts as professional trustees – can be an excellent choice. But they too can be expensive, and as individuals they present the risk of not outliving the beneficiary.

The option with the best combination of advantages and slightest of disadvantages are non-profit organizations that specialize in special needs trusts. They know the subject matter, and are set up for it. I tell my clients to investigate them, starting with an internet search. And then I tell them that they likely will not find a better one than PLAN (Planned Lifetime Assistance Network of California).

I wish I could say that PLAN pays me to say that, but to the contrary, PLAN obliges me to pay for my own travel expenses when I attend its board meetings in L.A., and about once a year it sends me a request for contributions. No, it is for a more virtuous reason that I say it, and why I serve without compensation on the PLAN Board of Directors: I believe in the organization.

PLAN is all about helping people who need help – those persons with mental illness and those persons who care for them. PLAN is not about making money. As PLAN is a non-profit organization, maybe that should be obvious, but we see plenty of non-profits who use an inordinate amount of their revenue to pay salaries and expenses of their principals. PLAN's staff is modestly compensated; none are overcompensated.

PLAN's rules require that a majority of board members be family members of persons with mental illness, and/or those

persons. That is what qualifies me to be a board member, and it is what ensures that the organization's focus will always be the care of people who need it, and not the monetary enrichment of people who possibly don't.

PLAN is staffed by people who care. The Director of Legal Affairs, the former Executive Director who still performs many of her former duties, and the Communications and Client Relations Officer all have family members with mental illness. They're running the show, and they're doing it for the right reasons.

My endorsement is not unconditional. What happens in the future, after our deaths, what will be the quality of PLAN's staff and services then? Take Bruce Lewitt, the Director of Personal Support Services whose personal attention to trust beneficiaries is the stuff of legend. He seems eternally youthful, yet presumably is mortal. Who does his job and the jobs of others in the future will be key in the continued excellence of the organization. Because of the way PLAN is set up, and because of its history and its present, we have good reason to expect smooth successions, and that continual skill and eminence of PLAN as a trustee will continue. As will my endorsement.

There are other effective trustees of special needs trusts out there. But none in my opinion superior to PLAN.

*\*Baron L. Miller is an attorney in private practice in San Francisco who specializes in estate planning for California families of the mentally ill. He is a long-time NAMI family member, an advocate for the rights and interests of families of the mentally ill, and a board member of Proxy Parent Foundation. He does not charge for telephone consultations on the propriety of making payments for the benefit of an SSI recipient. He can be reached at 415.522.0500.*



## Bruce's Yams



My husband Bruce is the Director of Social Services for Proxy Parent Foundation. Recently, he came home with an unusual item in his briefcase—a colorful metal can, labeled 'Bruce's Yams'. I thought perhaps it was one of those impulse buys that signals a smile he wanted to share with me.

"It's a gift - from Laurie," he explained cheerfully. Laurie is one of Proxy Parent Foundation's trust beneficiaries. Laurie had honored Bruce with her gift. "One of my favorites", she added.

Bruce first met Laurie almost twenty years ago, shortly after the death of her parents, who had set up a Proxy Parent Foundation trust with us a few years before. They were keen on the fact that Proxy Parent Foundation offered Personal Support Services since Laurie had significant trouble navigating daily life's numerous challenges. While she was still living in the family home, Laurie's parents looked after her as best they could, but once they were gone, Laurie had a very hard time dealing realistically with any kind of structure. She had been receiving public benefits, but she was unable to manage the funds.

Laurie found rules and boundaries very difficult to accept. She was prone to go off her meds, and abuse alcohol.

Laurie couldn't let go of the belief that she should be allowed to do as she pleased. The word 'trust' encouraged her to indulge in her belief that she was an heiress. Laurie was fixated on her perceived inability to comply with Proxy Parent Foundation's strict adherence to not only protecting her trust resources but also her public benefits. She argued for control of her trust and couldn't accept that her demands weren't being fulfilled. Because she

couldn't abide rules in a safe Board and Care where she had a private room, she walked out, saying she preferred total freedom and went homeless. Then she was in and out of the ER with a myriad of physical issues caused by her homelessness. Bruce enlisted the support of a psychiatric nurse from a public mental health mental agency and together they coaxed Laurie back into treatment, stabilized her living situation, and maintained her on medication and medical treatments.

Still, Laurie continued to campaign for her wish lists, while Bruce negotiated in good faith to chip away at Laurie's unhealthy habits and help her make better choices. Laurie would call Bruce repeatedly, at all hours, forgetting she'd already called, stating her demands, from the trust buying her a vehicle to live in, to having her favorite foods delivered to her door. In response Bruce would patiently explain time and again that the trust had to last as long as possible—hopefully through Laurie's lifetime. He reiterated to her about the rigid perimeters of the public benefits system. Laurie resisted. Bruce persisted.

Recently, Laurie finally arrived at the understanding that Bruce has been acting as a sort of big brother all along, always looking out for her, and having no problem saying "no" to requests that are not in her best interest. She has truly learned to appreciate that Bruce's measured distributions from the trust budget were calculated out of concern for her. She still asks Bruce for things she doesn't really need or that are out of reach, but that's part of their bond. It's a connection that has stood the testiness of time: saying "no" 90% of the time for 20 years.

## Book Review

By Joseph DeCarlo\*

### Bi-Polar Disorder for Dummies

by Candida Fink & Joe Kraynak, MA



All of us may have friends, family or co-workers who have been diagnosed with bipolar

disorder, which affects more than 2½ million Americans. The title of this book may sound out of place, however the book has excellent content. The book is broken down into 7 parts, including Part I, Getting Started, which has sections on finding a cause, prognosis and treatment options. Part III deals with managing the biology of bipolar disorder, Part IV deals with essential survival skills, Part V speaks to the fallout (hospital, work & financial), Part VI deals with assisting a friend or relative and Part VII explores tips for dealing with and managing bipolar disorder. This is an informative book that deals with the basics of bipolar disorder and is well organized in a way that is easy to understand and would be a great addition to your bookcase.

*\*Joseph DeCarlo is the father of a 42-year old autistic son "Joey" who also suffers from epilepsy. Joey lives at home with his parents and attends Project Independence, a Regional Center of Orange County funded program. Mr. DeCarlo is President of the Proxy Parent Foundation and can be reached at joe@jdproperty.com.*

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ADDRESS CORRECTION REQUESTED



Please let us know if you would prefer  
receiving our newsletter by email. Thank you.  
[info@proxyparentfoundation.org](mailto:info@proxyparentfoundation.org)

## BOARD OF DIRECTORS

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I wish to help support Proxy Parent Foundation

*a dba of Planned Lifetime Assistance Network of California*

Enclosed is my Tax-deductible donation of

\$ \_\_\_\_\_

- Please use this donation to provide Proxy Parent Foundation's help to those who need it in the "here and now".
- Please use this donation as our Proxy Parent Foundation enrollment donation.

(Enrollment donations must be \$1000 or more and can be made in payments.)

Name of donor: \_\_\_\_\_

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